Families' Lived Experiences, Quality of Life, and Health Equity in Childhood Nonsyndromic Clefts in Transboundary Haze Areas: A Hermeneutic Study with Border Health Nongovernmental Organizations

Siriporn Sasakul

Faculty of Dentistry, Nation University, Thailand

INTRODUCTION

Families living with childhood clefts in border and haze-affected areas face intertwined feeding, social, travel, language, documentation, and referral challenges. This study interpreted lived experience and health equity while incorporating the systemic perspective of a border health NGO.

MATERIALS & METHODS

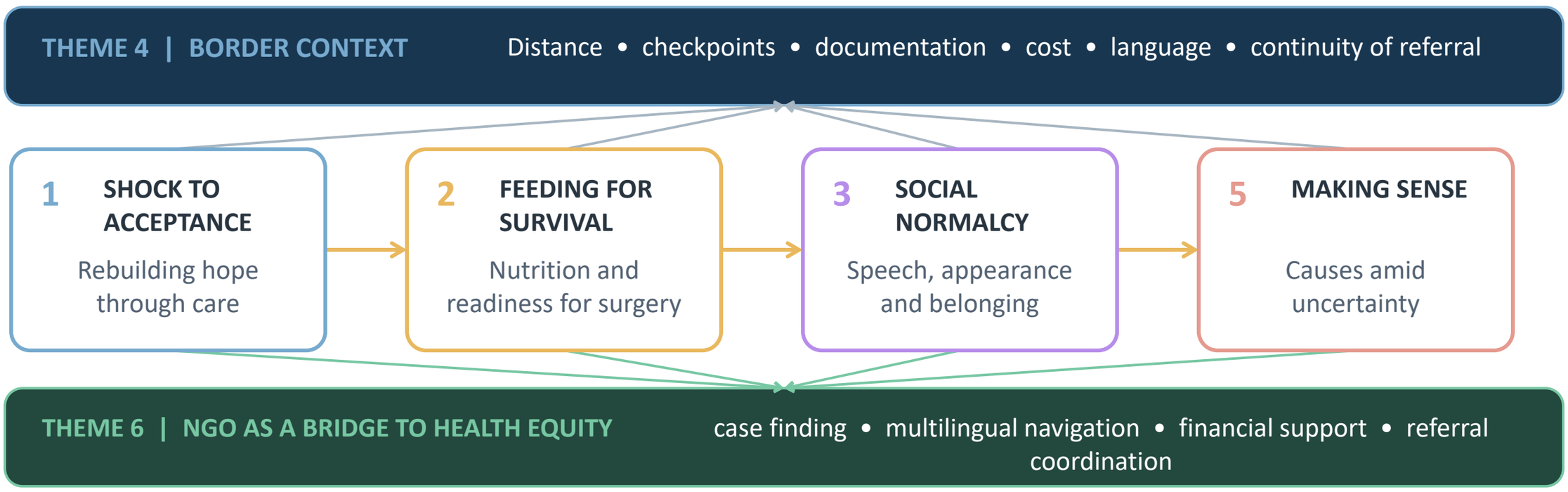
Hermeneutic phenomenology (van Manen) with purposive sampling. Family and NGO narratives were analyzed separately, then synthesized using the 6 phases of reflexive thematic analysis. Ethics approval: HREC-UP-HSST 1.2/188/68.

SAMPLE BREAKDOWN: 15 COMPLETE TRANSCRIPTS

Data-source type	Transcripts	Perspective represented
Individual or family caregiver interviews	**8**	Individual family experience
Small-group or family discussions	**6**	Shared and contrasting family experience
NGO key-informant group discussion	**1**	Systemic border-health perspective (3 informants)

Unit of analysis = usable transcript file, not individual participant. Some transcripts included more than 1 participant or family.

RESULTS: HOW FAMILY EXPERIENCE INTERACTS WITH THE BORDER SYSTEM



VOICES FROM LIVED EXPERIENCE

> ***"When my child was born...I was deeply saddened."***
>
> FAM-LAO-09

> ***"She could not breastfeed, so we had to buy formula milk for her."***
>
> FAM-LAO-07

> ***"Border communities live far away and cannot access treatment."***
>
> NGO-01

Verbatim English translations from participant transcripts

POLICY IMPLICATIONS

- Multilingual counseling, information and reminders
- Cross-border case coordinators for referrals, documents and travel
- Needs-based family support and formal referral partnerships across hospitals, border agencies and NGOs

CONCLUSION

Family resilience alone cannot overcome structural barriers. Equitable cleft care requires family-centered services, multilingual navigation and coordinated cross-border referral pathways. Perceptions of haze and chemical exposure are contextual, hypothesis-generating evidence - not proof of causation.

References: Braun & Clarke (2021) | van Manen (2016) | Sommer et al. (2021) | WHO (2024, 2025)